Privacy & Security Tiger Team
<mark>Draft Transcript</mark>
January 18, 2011

Presentation

Judy Sparrow – Office of the National Coordinator – Executive Director
Good afternoon, everybody, and welcome to the Privacy & Security Tiger Team. This is a FACA Committee, so there will be opportunity at the end of the call for the public to make comments. Just a reminder please, workgroup members, to please identify yourselves when speaking.

Let me do a quick roll call. Deven McGraw?

Deven McGraw – Center for Democracy & Technology – Director
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Paul Egerman?

Paul Egerman – Software Entrepreneur
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Latanya Sweeney? Gayle Harrell? Carol Diamond? Judy Faulkner? David McCallie?

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Neil Calman?

Neil Calman – Institute for Family Health – President & Cofounder
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
David Lansky? Dixie Baker? Micky Tripathi? Rachel Block? I don't think Alice Brown or Christine could make it today. John Houston?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Wes Rishel? Leslie Francis?

Leslie Francis – NCVHS – Co-Chair
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Sue McAndrew? Lisa Tettero?

Lisa Tettero

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Joy Pritts?

Joy Pritts – ONC – Chief Privacy Officer
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Did I leave anyone off?

Peter DeVault – Epic Systems – Project Manager
This is Peter DeVault for Judy Faulkner. I had my phone on mute.

Judy Sparrow – Office of the National Coordinator – Executive Director
Yes. Thank you, Peter. All right. With that, I'll turn it over to Deven and Paul.

Deven McGraw – Center for Democracy & Technology – Director
Okay. Terrific. Thank you very much, Judy. Thank you, members of the tiger team, for joining us on this call today. Also, thank you to members of the public who are listening in, which we very much appreciate. We're going to spend our time today on this call continuing our discussion on some draft recommendations for patient matching.

Now, all of you should have received the document that I sent around with some draft recommendations based on the conversation that we had on our last call. I thought it might be more helpful to, rather than taking up recommendations in slides, which seem to sometimes have us focus on things in siloed or interconnected ways, a sort of issue at a time, to try to put together a document that laid out the recommendations as really a package. And also allowed us to do a little bit of framing with a sort of very brief synopsis on what we heard at the hearing, as well as some framing comments with a particular set of recommendations where our discussion from last week indicated that we really needed one so people could understand more fully what we said. I'm hoping that discussing them in this way will allow us to again think about even as we discuss each of the individual parts of a recommendations, which, by necessity, we have to do— We can't take them all on at once. At least as we do that we'll have an idea of how any one particular recommendation fits within an overall sort of constellation or fabric of other recommendations. Which I hope will allow us to be more focused in these discussions and help us get to consensus maybe a little bit more quickly, but we'll see how this works.

We will have the ability as we discuss the recommendations to share my computer screen where I have the recommendation draft up so that we can do a little editing on-line. Again, to try to help us get to consensus I think, as always, we want to try not to spend wordsmithing time getting it, time on the phone getting it absolutely perfect, because we have time to do that off-line. But to the extent that seeing it on-line and in front of us helps us to, again, come to consensus on the big concepts. I think that has certainly been helpful in calls that we've had previously and I hope it will be helpful on this call as well.

Paul, I don't know if you want to add to that before we jump in and then make sure that folks on the tiger team also understand the direction we're heading in.

Paul Egerman – Software Entrepreneur
I think you did a great summary, Deven. I would just point out our next conference call is, I think, February 14th and what we'd ideally like to do if possible is to complete the patient matching discussion this call. So if that's possible that would be great.

Deven McGraw – Center for Democracy & Technology – Director

Yes, we always like to shoot for strong goals. That's a good point. Does anybody else on the tiger team have any other questions about format, process? I'm hoping that you all actually got a chance to read through these recommendations ahead of time, but I won't poll you on whether you did or not.

All right. On that note, we're going to move into the discussion. I want to say again that we have just sort of put a big picture block on this discussion; we have some draft recommendations to discuss that are really in seven categories. The first is standardized formats for demographic data fields, when those data fields are used. Creating the culture of improvement through internal evaluation; in other words, internally evaluating matching accuracy. Improving transparency of both matching accuracy, as well as matching algorithms; achieving some accountability for achieving good matching; developing, promoting and disseminating best practices for patient matching. Supporting the role of the individual and patient in data accuracy and patient matching, and then the last area, which we really have not had a chance to get to at all and may need to have a separate call to discuss because it's a pretty rich category, is propagating corrections to data.

With that sort of very large picture in mind I'm going to turn it over to Paul so that he can lead us through the set of recommendations on standardized formats for demographic data fields. I'm going to go ahead and move to Share My Screen so that we can get some piece of the text up here.

Paul, I don't know if you want to—

Paul Egerman – Software Entrepreneur
Yes. I was just going to wait a second to see if the text came up on the screen—

Deven McGraw – Center for Democracy & Technology – Director
All right. Give me a minute.

Paul Egerman – Software Entrepreneur
—… about to do it.

Deven McGraw – Center for Democracy & Technology – Director
Yes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
While we're waiting, I have a question. I noticed in reading the document that we have all of the details accounted for in terms of the seven categories. Do we feel the need to put some kind of a summary about our overall confidence or lack thereof in the use of these technologies? We've got a lot of the details, but not an assessment. Is that something that we should or shouldn't focus on?

Deven McGraw – Center for Democracy & Technology – Director
Well, we definitely had— What do you mean by an assessment? We did, in our summary of the hearing, have some conclusions about no one-size-fits-all solution to this—

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I was thinking more along in an overall notion of confidence that when properly deployed these technologies are adequate or something along that line. It may not be the purpose of this group to address—

Deven McGraw – Center for Democracy & Technology – Director
I don't know. My own view is that I don't think that's necessary. I think we have a set of recommendations to achieve greater accuracy and accountability in the area of patient matching, but I don't know that it's our job necessarily to say the current methodologies that people use are either good or bad. But we do, if we thought that they were all perfect, I guess we wouldn't have any recommendations.

Paul Egerman – Software Entrepreneur
I agree with what you just said, Deven, although David also raises a good issue. I think the information that we had before in the PowerPoint slides that you just referenced—that this is not a technical problem—that there are human factors involved, those kinds of issues. That needs to be some sort introduction or assessment. I don't know if that's responsive to what you're asking, David, though.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Yes, that's part of it. I mean, obviously, this is an area not without some controversy and what I came away with from the hearing was a renewed, me personally, confidence that when deployed properly these techniques can work well enough for the meaningful use incentives to go forward. Now again, maybe we're not called on to render that judgment and I'll just keep that as a personal judgment, but that's kind of what I was just thinking. All of the details are here to make it work even better, but the sense I got was that it actually is possible to make this work pretty well.

Paul Egerman – Software Entrepreneur
Yes, so maybe we can put something like that in the assessment that sort of says because it's not solely a technical issue patient matching requires, somehow, a fair amount of oversight and attention and management and when that occurs an effective result can be achieved.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Yes. I like that language. That's kind of what I was looking for.

Paul Egerman – Software Entrepreneur
Okay.

Deven McGraw – Center for Democracy & Technology – Director
Okay. Sorry about that, Paul. I lost my Internet connection.

Paul Egerman – Software Entrepreneur
Yes, so we lost it— All of the sudden I saw a note that said nothing is being shared, which is awfully, I don't know, unitary or something, isolating. So are you trying to get it back?

Deven McGraw – Center for Democracy & Technology – Director
Yes, of course.

Paul Egerman – Software Entrepreneur
While Deven is doing that, I went ahead—

W
Hello. I'm on the tiger team call for Adam.

Paul Egerman – Software Entrepreneur
Hello, and your name is? Somebody just joined for Adam.

W
Not yet, just logistics.

Paul Egerman – Software Entrepreneur
I pulled up the Word document while Deven is working on getting her computer set up and I'm going to walk you through the first topic, which is standardized format. What we wrote in this Word document, what we tried to do was to write what we thought we heard at the last call. I don't know if we did it right. Hopefully there is nothing new.

The first paragraph basically says that there is no particular data field that should be required for matching. In other words, we're not requiring the use of any specific data field. What we say is when data fields are used for matching there are some that are commonly used and a consistent representation would help. So that's sort of like the preamble.

Then the first two—I see it's coming up on the screen now—sort of bullets underneath that A and B, if you look at A and B first. The first one says, "The Standards Committee should propose a standard format for data formats where data fields are commonly used," and it gives some examples. The second one says, "The Standards Committee should also develop recommendations on how entities should handle situations when information is not available." In other words, what do you put in for the data when the date is unknown, because that was an issue that was raised during the hearing.

Before going to item B, let me pause and see if people have any reactions to 1A and 1B.

Deven McGraw – Center for Democracy & Technology – Director
Yes, we tried very hard. I looked back at my notes from the conversation from last call and tried very hard to capture what people were getting at.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I have a question/comment regarding this section. I certainly don't argue with what we have here. What I'm wondering about is that it says, "The Standards Committee should propose standard format," which would imply to me that these formats would be required for EHR certification. I believe what we're saying is that these data fields would be required, with respect to information exchanged between organizations. Isn't that true?

Paul Egerman – Software Entrepreneur
Yes, that's true and you raise a good issue. Because the issue there is, as it relates to standardization, what are we standardizing and what are you going to test. Are you going to test it only on the information exchange side of the world or are you going to test it on the data entry side of the world? In other words, are you going to actually test to see if you enter an unknown date of birth it does the right thing? I'm open to a discussion of either one. I would make the observation if you test it on the data entry side it's a little bit hard only because it's in the architecture of these EHR systems. Some of them may have lots of different places where you might enter a demographic data.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
….

Peter DeVault – Epic Systems – Project Manager
One of the ideas—I think it was Wes Rishel that suggested it and I think I seconded it last time—was that the interoperability testing really needs to happen from data entry through to data transfer and reproduction, which would suggest that we do need to actually do testing at the level of data entry.

Paul Egerman – Software Entrepreneur
Actually, Peter, now that you say that, that's correct. That was what Wes said and I think that's a reasonable thing, so we need to add that, which I see has magically just occurred.

Deven McGraw – Center for Democracy & Technology – Director
Did I get it right?

Paul Egerman – Software Entrepreneur
Yes. Instead of under A, you might want to put it after A, B and C, however, but the concept is right.

Deven McGraw – Center for Democracy & Technology – Director
Okay.

Paul Egerman – Software Entrepreneur
Okay. So is that responsive to what your question was, Dixie?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Yes, but she's going to move that to the introductory?

Paul Egerman – Software Entrepreneur
No, after A, B and C.

Deven McGraw – Center for Democracy & Technology – Director
Somewhere in here, so it could be B.

Paul Egerman – Software Entrepreneur
Okay.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I see. Okay. Yes, I think that that clarifies things. Thank you.

Paul Egerman – Software Entrepreneur
Okay. So the second B was just a comment about unknown, because that was part of the hearing information; people having trouble with somebody putting in date of birth and putting 9/9/9, so somebody else then puts in a valid date. It may be a mismatch. That was the issue there.

Letter C is written the way it is about USPS validation/normalization program. The reason why we wrote it is sort of like a suggestion for the Standards Committee is that it didn't seem right that the Policy Committee would tell the Standards Committee specifically what standard to use, but there was some suggestion at the hearing that normalization of address information would be beneficial. When we discussed this separately I gave the example of a patient's address maybe is 123 North Adams Street. One computer system writes out North, N-O-R-T-H, Adams Street and the next puts an N. Adams St. for street and maybe the next system does Adams Street North. Somehow normalizing that according to the USPS standards I think would also be helpful, but this was put more as a suggestion for the Standards Committee to consider as opposed to this is what we want to do.

I don't know if people are comfortable with the way we phrased that.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Maybe I should ask David or somebody else who works for an EHR vendor, but it seems to me if this is really the same issue— It seems to me if we are mandating existing products that we are mandating existing products change. Perhaps change their data field for data entry that could have a significant impact on the existing EHR technology it would seem to me. It would seem to me it would be more important that if as you send out information perhaps in a CCD that that would be standard, but not the data entry.

Neil Calman – Institute for Family Health – President & Cofounder
This is a place where I think calling out the corrections at a point of data entry will be better for all of us in the long-run. It may be a little bit higher bar in the short-run, but in the long-run all of these systems are then going to need to figure out a way to convert. However, they put the data in in the first place to a standardized format. It also doesn't allow for the same kind of validation checking.

So right now, if you go into your GPS or whatever it is and you put in Main Street South and there is no Main Street South it just doesn't show up. So there's a validation piece, not just around addresses, but around formats for Social Security numbers and phone numbers to check to see if things are in valid format. We've just found that that's been tremendous and we had an opportunity to share some data with

another agency recently where they brought up on their screen their breakdown of patients and their zip code data, about 10% of their zip code data was just wrong. I mean that's just absurd no matter what you're doing, whether you're doing outreach or whatever, so I would think that we're doing the industry and providers a major favor by calling this out of something that should be done up front. We'll end up with more accurate data and in the long-run it will be better and easier for everybody.

Leslie Francis – NCVHS – Co-Chair
Has anyone called out the question of women with multiple married names and middle name, married name and normalization on that one?

Paul Egerman – Software Entrepreneur
Well—

Leslie Francis – NCVHS – Co-Chair
I would just flag that because—

Deven McGraw – Center for Democracy & Technology – Director
What would such normalization look like and who gets to set it?

Leslie Francis – NCVHS – Co-Chair
Well, the question is that the only reason I wanted to state it at all is that one of the difficulties in matching women may be name changes.

Paul Egerman – Software Entrepreneur
Leslie, that's correct. By explaining this, we did list the common demographic data fields that would be normalized or standardized and that does include name. Name is surprisingly complicated—

Leslie Francis – NCVHS – Co-Chair
Right.

Paul Egerman – Software Entrepreneur
How do you handle middle name? How do you handle middle initial?

Leslie Francis – NCVHS – Co-Chair
Exactly.

Paul Egerman – Software Entrepreneur
How do you handle the circumstances that you just described when a change potentially in somebody's last name, but also it's sort of important to look at name as one of the data fields. It's sort of the example you just described, Leslie, also emphasizes why it's important to do this, the USPS thing. Because if you have an exact match on address, you have an exact match on date of birth and a few other things and you have a match on the first name that's comforting, as it were in terms of trying to figure it out. So it's a good comment, but I don't think we want to dive into how the standardization will occur. We'll let the Standards Committee roll up their sleeves and do the hard work. We're just going to say, "Standardize it."

Leslie Francis – NCVHS – Co-Chair
Absolutely. I just wanted to flag the problem.

Deven McGraw – Center for Democracy & Technology – Director
Okay.

Paul Egerman – Software Entrepreneur
Great.

M
So the issue is still on the front-end or back-end?

Paul Egerman – Software Entrepreneur
Well, yes, that's the issue, although what's written here was—

Deven McGraw – Center for Democracy & Technology – Director
Is both.

Paul Egerman – Software Entrepreneur
Is both front-end and back-end. I guess I hear Dixie's concern, although—

Deven McGraw – Center for Democracy & Technology – Director
Peter raised it I thought.

Paul Egerman – Software Entrepreneur
That's right. Most of the really good EHR systems handle almost all of this stuff already and compared to all of the other things we're asking vendors to do with interoperability and vocabularies and things, this is not a heavy lift as long as we define it well. The other observation I have is I think it's already defined in the X-12 standards. It's just that people haven't been real compliant with it.

Peter DeVault – Epic Systems – Project Manager
I think that's the case.

Paul Egerman – Software Entrepreneur
Was that David who just said that?

Peter DeVault – Epic Systems – Project Manager
This is Peter.

Paul Egerman – Software Entrepreneur
Yes. So I think though in some sense there's an aspect of what we're saying here is sort of like you ought to cross the street when the light is green and not when it's red. In other words, the standards already exist for this. The problem is the vendors aren't following the rules. What we're really asking the Standards Committee is to make sure they're following the rules and to back it up to the source of the data, which is sort of what Neil Calman is suggesting is a good idea in this case.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
If Neil and David are fine with this, I certainly am.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Yes. I'm okay with it from the impact on the vendor. I think the real question is the impact on people who use these systems and have to go through training if you've changed something as fundamental as the way a registration screen works. That will generate far more criticism and complaint than the vendor community will give you.

Paul Egerman – Software Entrepreneur
Well, okay. I think that's a good observation, although I think we're starting to be very good at handling and receiving criticism. I think ... complaint and we don't have experience with that.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I'm with Neil; it's worth it. I mean this is—

Paul Egerman – Software Entrepreneur
I think it's worth it. It's a simple thing and I think it can make a difference.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Yes. No question.

M
All right. Let's move on.

Paul Egerman – Software Entrepreneur
Okay. So I think there's consensus on that. Let's move on to the second one.

Deven McGraw – Center for Democracy & Technology – Director
Oh, my goodness.

M
Actually, if I could, if we could go back to the second B.

Deven McGraw – Center for Democracy & Technology – Director
Yes.

M
I think there are actually two aspects here. One is recommendation to entities on how users should handle missing information, which is what's stated here, but I think there is also another piece, which is how should the system represent missing information when it's sending data out. So in other words, it's one thing to say, which it does here, that there should be recommendation on what to do when there's no known date of birth. There might also need to be a recommendation on what the system should send out in a CCD for date of birth when there isn't one that's known. Does that make sense?

Paul Egerman – Software Entrepreneur
It makes a huge amount of sense.

M
Yes and it would be part of the standard format definition.

M
Yes, exactly.

M
How you represent not known and unknown and all of those variations.

M
Or not collected. Yes. Exactly.

M
Not collected. Right. Not asked. Not collected.

Paul Egerman – Software Entrepreneur
That was very helpful.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Isn't that what we have in the current C, should also develop recommendations?

Deven McGraw – Center for Democracy & Technology – Director

I think that's about normalizing an address isn't it?

Paul Egerman – Software Entrepreneur
C is about addresses.

Deven McGraw – Center for Democracy & Technology – Director
Yes.

Paul Egerman – Software Entrepreneur
C is about addresses and it references—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
No. I mean we added a B here and so I mean the second B.

Paul Egerman – Software Entrepreneur
Yes. That's correct.

Deven McGraw – Center for Democracy & Technology – Director
Yes, I just added that language, Dixie.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Right and I'm talking about the second B that's on the screen. I believe takes care of this issue of missing data.

Deven McGraw – Center for Democracy & Technology – Director
Yes.

Paul Egerman – Software Entrepreneur
That's right. So with this clarification that we want to also make sure it's clear how the missing data is exchanged are we all set with number one and on to number two?

M
Yes.

Paul Egerman – Software Entrepreneur
Okay. Let's go on to number two. Deven, why don't you lead us through this?

Deven McGraw – Center for Democracy & Technology – Director
Terrific. All right. So this is a set of recommendations that gets to some of the human factors issues, including the training and that is that there are internal. We heard a lot at the hearing about the need to sort of put into place internal programs for evaluating how effective an entity is at matching. So we've got a set of recommendations here that we definitely need to discuss and even when Paul and I were putting them together, we had some questions that we wanted to tee up in addition to putting some draft recommendations in front of you. So we have three recommendations here:

Healthcare organizations and entities should routinely evaluate the effectiveness of their matching strategies and achieving matching accuracy. So this would include individual providers and institutions, as well as HIEs to address liabilities concerns that might be raised with such sort of internal review. Such an evaluation or analysis could be done by a patient safety organization. This was, quite frankly, not something that got surfaced at the hearing, but a thought that I had based on liability concerns that did get expressed.

The second recommendation is that organizations and entities should use such evaluations in internally improving their matching accuracy and then the Office of the National Coordinator should explore a

strategy for requiring such evaluations to be reported to improve the evidence base on what works in patient matching and also enhance public transparency. So the idea here was not necessarily to, at this point, require that such evaluations be reported, but to instead ask ONC to review it. In my view this review would include whether at an early stage you would ask that those evaluations be confidential, for example, and used solely for purposes of examining what works versus coming up with a longer-term transparency and accountability strategy for moving the industry to certain benchmarks, but we have a number of questions about this. So do we know enough today about how to effectively measure patient matching accuracy in order to put a recommendation like this forward? Do we need to really generate and disseminate best practices first and do we have a mechanism for generating best practices if people are not sort of moving forward on measuring what they're doing and how effective it is?

Then, assuming that we actually do want to encourage some internal quality improvement in this area, do we think we're at the stage where ONC should be using policy levers to either encourage or require this measurement? Such as, for example, by requiring internal improvement programs on patient matching as part of grant programs for HIEs, for example, or if this were part of a later stage, meaningful use criteria.

So we didn't get a lot of time to discuss this on our last call because we had spent a lot of time on the standards piece, which is important and is part of the reason why we were able to get through that one so quickly today. But this one, I think, is worth talking about further. I think we also need to consider sort of what's doable today versus what we might strive for tomorrow and what types of recommendations are likely to move the needle.

Leslie Francis – NCVHS – Co-Chair
Deven, I'm not sure why you'd want to recommend to organizations how they should deal with their liability concerns.

Deven McGraw – Center for Democracy & Technology – Director
Okay. That's fair. I think I added it as a way to potentially keep the liability concerns from preventing us from moving forward, but I'm not wedded to it. It was just a suggestion.

Neil Calman – Institute for Family Health – President & Cofounder
I would agree with that comment. I also think that C is unnecessary. There are lots of ways that we learn new science and learn things. I think I'm just cautious every time we say that we're requiring people to report on stuff and ONC is going to evaluate it and that we're building overhead into these systems, both at the user and also at the regulatory end. I think there are other ways of figuring out best strategies, the same way we're learning about best strategies for decision supports and other things by people reporting on their research and on their progress. So I would not be in favor of having this be something that everybody reports back to ONC on in order for ONC to try to extract some new knowledge out of it, but I don't feel terribly strongly about it. I just don't think this is one of those places where we should push that.

Peter DeVault – Epic Systems – Project Manager
I think I'm going to end up at least partially disagreeing with you. I mostly agree with the spirit of what you just said, but I do think that there is maybe an area where a couple of different things we could report on might be useful. I'll resurface an argument that I've kind of made ... on the last call, which is that I think it would be very difficult to report on patient linking. I'm not even sure we would know how to describe numerators and denominators correctly, but what we might do is have people report on something that I think is a pretty good proxy variable for accuracy, which is potential duplicate patients in a system. Having potential duplicates, which basically means you've created duplicate records because you've not collected enough information or you've collected inaccurate information and not found the patient that showed up in front of you because that happened upstream of you. That's a pretty direct indicator of how accurately you're going to be able to match on patients. So I'll just throw that suggestion out there again; that that might be something that we would like to see people report on and try to extract some knowledge about what's possible and what's acceptable.

Paul Egerman – Software Entrepreneur
How do you know many duplicates you have?

Peter DeVault – Epic Systems – Project Manager
Basically, you run a hypothetical patient match all of the time on your patients in your database and so if I'm looking at Peter DeVault's record in the database I look to see if there are any other records in the database that would match if a patient link request were made on that patient. If there are that goes on a list of potential duplicates. It might be that there's another Peter DeVault living at the same address with a similar date of birth or it might be that somebody inadvertently created a duplicate record, so it's a potential duplicate.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
That would be a function of the settings of your algorithm. You could make that number arbitrarily large or small, depending upon your definition of what potential means. How would that help?

Peter DeVault – Epic Systems – Project Manager
Yes. I mean that's a really good point. People do play with those algorithms today internally in an effort to clean up their patient database and keep it clean.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Right.

Peter DeVault – Epic Systems – Project Manager
Certainly, having the potential duplicates low is good in itself. It drives a whole bunch of other processes and it's a great question how you would want to control that so that the numbers that you're getting are meaningful and normalized.

(Overlapping voices)

David McCallie – Cerner Corporation – Vice President of Medical Informatics
For every reduction in potential duplicates, you probably create false positive matches, which are, according to the testimony, more harmful on average than duplicates. So I think I'm kind of with Neil's point; this is David again; that whereas you should try to measure these things and make it better is a great idea, specifying the details of how you'd actually report it out would be really pretty difficult.

Deven McGraw – Center for Democracy & Technology – Director
Yes. I think the other thing is I had gone back through the written testimony also in pulling this together, especially after we had a bit of discussion about sort of whether we were ready for public reporting and holding people accountable to certain levels of performance, either at the front-end or at the exchange end of a transaction. The one thing that struck me was that while lots of testifiers were really very well aligned in terms of the issues and the need for better evidence and the need to measure, when it came to sort of setting specific standards and what those would be we had very little testimony. One of the ones that I tried to finesse that in the draft was to ask ONC to explore it further as opposed to saying these internal measures should be publicly reported. So, hence—

M
To explore the algorithms or to explore reporting on your experience?

Deven McGraw – Center for Democracy & Technology – Director
Explore reporting. It says, I mean after Neil's comment I sort of cut it out and moved it to the bottom, "ONC should further explore a strategy for requiring these internal evaluations to be reported in order to improve the evidence base on what works in patient matching and also enhance public transparency."

Paul Egerman – Software Entrepreneur
Deven, how does ONC do that? Do they say, "Okay, tiger team, explore this for us further?"

Deven McGraw – Center for Democracy & Technology – Director
Well, I suppose that's one. I think that sort of, without a lot of internal measurement going on, I think we at this point could not give ONC an answer to this question. I don't think. Perhaps we could—and maybe Carol alluded to this with the small group idea—gather some of our testifiers and maybe some folks that we didn't hear from to try to drill down and get a number. But the overwhelming impression I got from reading back through the testimony was the need for more data and the need for more measurement of what works and what doesn't. I suspect until you have a little bit more of that data it's sort of hard to then move to a strategy of well then thou shalt measure. But I guess I was putting the idea on the table as something that ought to be pursued in the future given that really health IT adoption and HIE is a long-term strategy that we hope will take off substantially in these early stages of meaningful use, but there will still be lots of work to be done. That was my thought, but—

David McCallie – Cerner Corporation – Vice President of Medical Informatics
It seems like maybe there are two separate ideas here, one of which is the notion of figuring out how to do a better job with these algorithms, which is, I think, a legitimate research question. I think Shawn ... bemoaned that it was difficult to get funding for research on patient matching strategies and it was difficult to publish the work so there was not a lot of encouragement for academics to improve the field. He said we should try to do that. But then, the second point is the transparency question, which I think is the next big item, isn't it?

Deven McGraw – Center for Democracy & Technology – Director
Yes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Reporting is really a transparency question.

Deven McGraw – Center for Democracy & Technology – Director
Yes. It is.

Neil Calman – Institute for Family Health – President & Cofounder
Remember, we've talked about this before. This is sort of context related, right? So if you can alter your algorithms, you can end up with zero false positive matches by requiring people to match character-by-character on 12 different fields in order to call it a hit. But actually, what we do when we try to find records within our own system, which has 100,000 records is we start by using very few characters because of the possibility that somebody mistyped a first name or mistyped the last name. We don't even put the full name in to try to obtain a match. Then what you end up with often times is three to five to ten names that look like the match. Then you can look to see if there's one that matches exactly. But the point I'm trying to make is that if we're really trying to promote exchange there is a balance here and so it might very well suit a situation where I get to look and say, "Is this you? Do you live at this? This address isn't exactly right," or whatever. And yet, reporting on duplicates in a situation like that might not really give you accurate information. So I think as you try to promote exchange, you want to open those things up a little bit so that maybe the provider is getting a choice of two or three potential matches and having an opportunity to vet those against who is real rather than trying to make their match most exact. So they can report to ONC that their matching accuracy is 0.001.

M
There's a big difference between human attended matching, like Neil was describing, and unattended matching that might be done by a back-end system.

Deven McGraw – Center for Democracy & Technology – Director
Right.

Neil Calman – Institute for Family Health – President & Cofounder
So I wouldn't want somebody to plug my blood transfusion in based on that, but I might want somebody to at least say, "There are three potential Neil Calmans. Which one are you?" before they download my record into their EHR.

Deven McGraw – Center for Democracy & Technology – Director
Right, because ideally you don't want to expose more information that could be a privacy risk in order to achieve a match number versus using the minimum amount of identifiers that you need to in order to make the match, but achieving as good a level of accuracy as you can with that strategy.

Paul Egerman – Software Entrepreneur
It's also an issue of it's hard to figure this out because there are so many different care environments, right? I mean things might be totally different for a small, rural hospital. They might have a totally different set of issues or rural healthcare may be very different or an extended care facility could view this differently.

M
Also, the number of patients in your database is going to influence this.

Paul Egerman – Software Entrepreneur
Well that's right.

M
You're much more likely to get duplicates if you have a million patients in your database than if you're a single provider's office with 4,000 patients.

Paul Egerman – Software Entrepreneur
That's right. So I'm listening to all of this and I'm starting to think that what you said, Neil, in the beginning was right; that we ought to stop with points A and B; that A and B are good things because they're sort of like consistent with the whole learning healthcare system that's a basic ONC strategy. So to say this is; I don't know if we're saying it's a best practice, but organizations need to eternally evaluate their matching accuracy and give some information about that. I think that's a good statement, but I don't think that we're anywhere near close to requiring them to report it, a matching accuracy, or even to report anything else, because we don't even know what the metrics would be that they would report.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I agree with all of these comments and I would also like to suggest if we consider what David was pointing out, that really number three is really what we're going towards, so I would like us to consider deleting two entirely and just promoting transparency instead.

Deven McGraw – Center for Democracy & Technology – Director
So no internal measurement? That's not what I heard. That's not the direction I heard the conversation going.

M
No, not at all.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Number three says, "The efficacy of those strategies." That is internal measurement.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

We're just kind of moving the dirt under another rug, because we now have to define what gets made transparent. Is it an actual statistic? I mean is it a true positive/false positive/recall/precision/accuracy measure?

Deven McGraw – Center for Democracy & Technology – Director
I'd like to say I really like that metaphor of the dirt under the rug.

Paul Egerman – Software Entrepreneur
Thank you, Deven.

Deven McGraw – Center for Democracy & Technology – Director
I'd like to stay with the rug that we were on if we have consensus on it. This idea that the learning healthcare system ought to also embrace patient matching in terms of organizations should be evaluating how good they are doing this.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
That's fine with me to just leave it as A and B, but I definitely agree that we shouldn't be requiring them to report another—

Deven McGraw – Center for Democracy & Technology – Director
Okay. It's gone. Now, is there something that we want to say more specific about the policy levers? We've sort of told ONC—we say actually that A is sort of more of a statement of what should happen— both A and B are sort of this is the state that we would like to see. They're not really framed as specific recommendations on what ONC should do in order to produce those outcomes in terms of its own policy levers, whether through grant programs or whether this is sort of more something that HHS should focus on overall.

M
So one option is to encourage them to promote study or research—

Deven McGraw – Center for Democracy & Technology – Director
Right, which we do actually have. There is another set of recommendations on developing, promoting and disseminating best practices that does call on HHS to support research along these lines. But this is in terms of we sort of have a wishful outcome of healthcare organizations and HIEs internally improving their processes here, but do we want to take that to the level of ONC should use its policy levers to either encourage or require this?

Paul Egerman – Software Entrepreneur
I don't see how ONC could do that, especially since we haven't defined the metrics, how the measurement is going to occur. To me it would be like saying ONC should use its policy levers to require that physicians make people healthy. It sounds good, but what are they supposed to do?

Deven McGraw – Center for Democracy & Technology – Director
Right. That's a good question. Hence, why it's in here as a question, because I think we were struggling a little bit on our last call with the idea of yes, we think this is valuable, but what are the incentives that can be put in place to make this happen. Especially when we probably have a lot of organizations out there who, unlike the entities that testified to us, don't have a real clear idea about how to measure how effective they are in achieving matching.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I'd like to focus on best practices as opposed to specific measures just because of the huge variation in circumstances and settings. I also like the notion that this is a legitimate research endeavor. I mean it's kind of the backwater of health informatics research, but it is obviously very important until such time as we have more unique ways to identify people, which may or may not ever happen. Apologies to the bad

metaphor about dirt and rugs, but when we get to the transparency section we will have to decide what gets made transparent, which is going to raise this same question again.

Deven McGraw – Center for Democracy & Technology – Director
Right.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Maybe we could go to that question and then come back?

Deven McGraw – Center for Democracy & Technology – Director
All right. That's a fair point. All right. Leave this as is for now.

Paul Egerman – Software Entrepreneur
Let's move on to the transparency. It's a great transition for transparency and the metaphor of dirt under the rug. This is a see-through rug that we're talking about here. I think, David, you did a good job of describing the challenges, which is what are we talking about in terms of transparency, what do we want to be known. It says here, "Providers and entities," that includes HIEs, "Should be transparent about strategies used to match patients and the efficacy of those strategies." Then it says, "HHS should gather and disseminate evidence of effective patient matching strategies." What do we think about what's written here? What should it say for promoting transparency?

Neil Calman – Institute for Family Health – President & Cofounder
I think this is so far out of range for what a consumer is going to be able to understand or interpret. I mean they're not even using like cardiac mortality data to decide where to go and get their hearts operated on. For somebody to think that they're going to know that somebody in a provider system is going to actually have a conversation with somebody about their matching success and matching strategies. And at what point will that conversation take place or will this be on a public Web site that somebody is going to actually want to look at? How are they going to interpret that? I mean just with all of the same qualifications of the discussion we just finished how would somebody interpret these numbers? I don't understand what the transparency—

Paul Egerman – Software Entrepreneur
Here's another way to look at transparency. I think your comment there makes sense, Neil. Maybe instead of the public we're talking about vendors being transparent with the purchasers; that—

Neil Calman – Institute for Family Health – President & Cofounder
Vendors being transparent with—

Paul Egerman – Software Entrepreneur
Yes. In other words, it was actually very helpful during the hearing that the people from IBM and the people from Microsoft described how they do things. It would seem to me that that would be something that we'd want to encourage, that vendors of different services would describe their algorithms or their strategies so the purchasers could have additional information.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
My only concern about that is I suspect the vendors would also say that your success in using their software is based upon how you configure it.

Paul Egerman – Software Entrepreneur
Sure.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
And I'm sure that there is as much capability to configure the matching algorithms as you, as an organization, see fit. So—

Neil Calman – Institute for Family Health – President & Cofounder
And if we don't have a standard way of reporting on accuracy how would anybody interpret? I mean I'm not an expert in this, but if I were looking at two different systems how would I interpret that? How would I even know which one is better in my particular circumstance with my patient population and with my staff? It just doesn't seem like this is meaningful. I mean we're doing so much here I guess I feel like my focus is to try to keep us on things that are truly meaningful and not over burden this with a lot of things that's not going to really be meaningful to the community.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Speaking as a vendor, clients don't usually have too much trouble extracting information like this from the vendor if they're really serious about the product anyway. The vendors are usually anxious to answer questions necessary to satisfy a sale. Then second, basically in line with what Neil just said and others, that performance of these algorithms is so dependent upon the population in which they're deployed you couldn't pre-determine the deployment. I mean the performance. You'd have to actually deploy it to find out how well you did or do extensive statistical sampling, which I don't think anybody would consider a necessary step.

Paul Egerman – Software Entrepreneur
Sure. Your comments, David, make sense. I mean as I think about it, if I were a vendor and I was proud of how I did patient matching, I thought I had something particularly special, I would just say so. So where are we coming down on this? Are we saying that we don't want to say anything about promoting transparency? What's—?

Leslie Francis – NCVHS – Co-Chair
I want to put in an or on the patient side or the consumer side from a privacy perspective, because you're talking about the accuracy point. But the other transparency question is what kinds of information are you using and all of the concern about patient identifiers and so on goes to that kind of question, so consumers can understand whether you're using birth date or middle name or Social Security number. They might have much more concern about one kind of information being used in the algorithm than in another. When I read that, I read it as about transparency, not just about accuracy, but transparency about what information elements are being used from a consumer perspective.

Paul Egerman – Software Entrepreneur
Yes. So you're saying the issue here is not transparency about how the matching occurs, but it's transparency about how the data is getting used.

Leslie Francis – NCVHS – Co-Chair
Right.

(Overlapping voices)

M
I'm sorry.

Leslie Francis – NCVHS – Co-Chair
I just said what data elements are being used.

Paul Egerman – Software Entrepreneur
What data elements are being used.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I mean the counter for that—I'm sensitive to that. I think that's a good point, the counter to it being too transparent about how you do matching is, as we heard from one of the panelists, that you could invite fraud.

Leslie Francis – NCVHS – Co-Chair
Yes.

Deven McGraw – Center for Democracy & Technology – Director
Yes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I mean in some ways you really want to encourage your consumers to be as precise as possible when they present themselves with these demographics so as not to have mismatched records, but knowing ... subset of the consumers who exactly want to create mismatched records.

Paul Egerman – Software Entrepreneur
Yes. Getting back to Leslie's comment, which is a very good comment, we already did a transparency recommendation, which did not get yet approved by the Policy Committee, but that's different. What she's suggesting, I think, is a different issue than what we're trying to do here, right? Which is really transparency about matching strategies and algorithms—?

Deven McGraw – Center for Democracy & Technology – Director
Right. I have an idea.

Paul Egerman – Software Entrepreneur
—a good one that we should probably revisit, but it's not really directly attached to the ... matching issue.

Deven McGraw – Center for Democracy & Technology – Director
Right. No, it's not. I have an idea that there is a set of recommendations in the next category on accountability that focus a bit more on the way that health information exchanges. And other what I term to be infrastructure entities that match patient data for exchange, whether there are, again, with a focus on getting the match right for exchange purposes, whether this is an area in which we can maybe promote some greater accountability. I would almost put Leslie's point in the category of what types of data fields are used to make the match, such as in a master patient index, for example, that maybe we might take that up in that section.

M
So this is the McCallie rug approach?

Deven McGraw – Center for Democracy & Technology – Director
Right, removing the dirt to the dining room rug.

M
Right. So around this topic, item three, I'm hearing there is no consensus about doing anything—

Deven McGraw – Center for Democracy & Technology – Director
Yes. I think that's right.

M
So it's sort of like in my notes I'm like putting a big X through item three and then I'm moving on to four.

Deven McGraw – Center for Democracy & Technology – Director
Yes. I think that's fair. All right. I'm going to X it.

M
And we now have a very large pile of dirt under this rug.

M
Well—

M
I'm just kidding.

M
Not necessarily. It's a little lumpy, but—

Deven McGraw – Center for Democracy & Technology – Director
All right. We've moved. So again, this is under a title of accountability. As I started to mention just a moment ago, we're talking about the way that this is framed and this got introduced a bit by Carol on our last call, but we definitely did not have a lot of time to talk about it. I subsequently had a follow-up call with Shawn ..., who I recalled talking a bit about what they did in the Indiana network for patient care. He confirmed with me that they do require their participants to clean up their data to participate, but they don't necessarily hold them to a particular standard of accuracy in order for them to participate, but it is definitely something that they, as an HIE, pay some attention to in order to advance greater accuracy in exchange.

The way we've got these worded; and again, these are draft, so completely up for discussion; is the idea of HIEs and other infrastructure entities that match patient data through exchange, such as through an index, should be required to set and be held accountable for accuracy standards. As the evidence is gathered and disseminated about the efficacy of matching strategies ONC should convene stakeholders to develop measures of accountability for matching accuracy that can serve as benchmarks.

Providers and entities should be required to adhere to policies regarding what should be done with data that is incorrectly exchanged due to the wrong match.

Here, this is where we actually do have the breach notification provisions might actually be applicable here, because if you get information you weren't supposed to have about a patient and you don't return it I think it's arguably a breach.

Neil Calman – Institute for Family Health – President & Cofounder
I don't know what returning it means in an electronic environment. I guess not accepting it or something like that. But again, my question here is are we looking at something that's purely mechanical, that has no human intervention at the point of the match? If so, if there is that kind of intervention where I get to look at something and say yes, this does match or doesn't match, how does the HIE know about that. For example, if I do take information in and later find out it's not correct, how does the HIE know about that and monitor it? These are ignorant questions, but—

Deven McGraw – Center for Democracy & Technology – Director
Well, no. I mean I think if you get a match from an HIE, presumably one would hope there would be procedures for you to follow through and notify the HIE that, in fact, the data they sent you is not correct.

Peter DeVault – Epic Systems – Project Manager
I'm a little bit confused about why we're singling out HIEs because in just as many use cases it's an EHR system that's doing the patient matching and accepting data or asking for data based on accurate or inaccurate information. Based on the last conversation, if we're not willing to hold EHR systems up to certain standards then I'm a little confused how we hold any other kind of system up to those kinds of standards.

Deven McGraw – Center for Democracy & Technology – Director
That's a good point, Peter. I think in part I focused on HIEs here because this is one area where arguably the Office of the National Coordinator has a tool in the form of grants and/or potentially NHIN conditions of trust and interoperability, which the Governance Workgroup set out the process for establishing, but we don't have any of them yet. That we would have some vehicles for asking for a level of accountability that wasn't necessarily present at the source systems where, at least based on the testimony we received, I thought we heard we have less of a problem there than with respect to the ability to match, effectively match records when you're away from the source. Which isn't true, I guess, of all HIEs, because one could presume that if you've got a centralized database the HIE is in fact the source of the data. But I was sort of looking at where we had some additional measures of accountability and in many cases be farther from the data source issue, meaning there would need to be some additional attention paid, arguably or likelihood of error being higher.

Then I think the third thing was—again, picking up on a line of discussion that began in our last call, but that we did not finish—was Carol's analogy of the you're not tall enough to get on this ride. That for participation and ability to participate in a network the other participants have to trust that you have matching processes that are accurate and that getting this right at an index level might be the right place to start.

So I throw all of that out there as a rationale for why I focused on HIEs, but I don't disagree that the problem is not just there. I was just trying to think of ways to move the needle.

Paul Egerman – Software Entrepreneur
So this issue of you're not tall enough to get on this ride, rather than say organizations need to be held accountable would it just be appropriate to say that matching accuracy is an issue that should be considered as part of the NHIN governance?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I think it's more a technology issue than it is organizational issue, because whether you're talking HIEs or individual providers, they're going to buy technology that does this NPI function. So I think that to require them to be accountable as entities seems to be pointing in the wrong direction.

Peter DeVault – Epic Systems – Project Manager
I would actually suggest there's a lot more mix of technology and policy and management than it is just technology. Let's just assume a generically decent system out there that has an NPI and a registration front-end; as we heard in the testimony several times the data that you have in the system is typically not any better than the data that's put into the system and often worse. Really, in the hospitals that I work with there's a lot of effort spent on making sure that registrars are trained correctly to enter data correctly and to look for those duplicate patients and to have process and polices in place to keep the data clean.

Paul Egerman – Software Entrepreneur
Everything that you just said, Peter, makes sense.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Yes.

Paul Egerman – Software Entrepreneur
I suspect that when Dixie was talking about technology though she was thinking of it from the HIE perspective where they may not have any or very little direct contact with patients. They're simply taking stuff in from multiple sources and trying to match it somehow into something.

W
Yes, but even if they don't have contact with patients does that mean they don't have contact with their participating providers?

Paul Egerman – Software Entrepreneur
That's correct. Good.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
It strikes me that if there was anything that we wanted to try to come up with a measurement for it might be a measurement of the performance of the data capture process under the assumption that that has more determinant than anything else on the accuracy of downstream record matching.

M
That's exactly what I was trying to get to through a proxy variable of duplicate patient records, but I completely agree with that sentence.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
That makes sense. I understand your point now. I mean it would be possible, for example, to define what percentages of dates of birth are captured, what percentages of middle names are captured, etc. I'm not sure that we should do that, but that's doable I think.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Peter made a really good point; that within a healthcare organization, obviously, a lot of this is processed, but as Paul pointed out, I was really talking about an HIE that tends to license technology to do that. So maybe in this area of accountability we do need to separately and distinctly address those two.

Deven McGraw – Center for Democracy & Technology – Director
Well, what other accountability on the technology do we need, Dixie, other than what we already have in terms of asking for standards to follow up with EHR certification requirements that are tested on the demographic data field representation?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I don't think any, which means that if an HIE licenses a certified EHR who presumably ultimately we're going to have this NPI function within the EHR, then maybe A is no longer needed.

Deven McGraw – Center for Democracy & Technology – Director
Well, but I guess I'm arguing that this whole set of recommendations doesn't get to the technology aspects at all and wasn't intended to. It's intended to get to more of the non-technology/human factors aspects of it, of which if present in HIE, I would think not with respect to interaction with patients necessarily, but with providers and also certainly present at the provider level in terms of accurate data capture.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I don't think there's much human interaction at the HIE level. I think they're going to depend on people to accurately match locally to send them with the right identifier for the patient. I can see HIEs reaching back to make sure that a patient's record is identified correctly.

Paul Egerman – Software Entrepreneur
Yes, that's right, Dixie, but you could imagine an HIE saying to a particular group practice or even a hospital or a laboratory or somebody saying, "Hey, your stuff is a mess. Unless you clean it up we're not going to deal with you anymore."

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Yes.

Paul Egerman – Software Entrepreneur
That's what I meant by governance—

M
Right.

W
Yes.

M
Or that there's an enormous amount of missing data—

Paul Egerman – Software Entrepreneur
Yes. Right. Or you've got a consistent problem you're getting nothing but complaints about ... that you don't have dates of birth. Can you give us a plan as to how you're going to fix that so we have fewer problems going forward? That's what I meant by governance issues. That's NHIN governance or perhaps even HIE governance if there is such a thing. I could see them doing it, but I don't see how you could do a whole heck of a lot more. In other words, the idea of establishing specific standards until we know what the metric is, I don't know how you can tell them they've got to develop standards, because nobody knows what it is getting measured. It's still an issue of different organizations having different sensitivities and different issues around these things.

Deven McGraw – Center for Democracy & Technology – Director
Well, but I think ultimately we don't necessarily want to have nationwide people setting their own terms about what's acceptable versus ultimately bringing everyone up to as high a level as is reasonably possible, because nationwide data exchange requires that you trust that the other entity is making the same reasonable efforts you are to appropriately match data. Otherwise, I don't know how you could trust that the data that one entity sends you is accurate.

This has been one of many dilemmas that we faced in trying to pull these recommendations together is that we've got not a great evidence base about what works ... state of people exploring this and implementing improvement programs. Yet, a strategy that in the short-term looks at internal quality improvement doesn't necessarily serve you well for the long-term where you want to build a set of conditions of trust that will provide incentives for people to engage in nationwide exchange. Because they trust that the other entity is also being careful and responsible in terms of accurately matching patients.

So I think that was my dilemma here but, Paul, along those lines maybe accuracy standards is the wrong term here and that what we're looking for is that HIEs develop, as part of their governance, matching accuracy programs for their participants or require their participants to have good data quality. I mean these are not well wordsmithed recommendations, but I want to make sure that I'm first heading us into an area where we appear to be achieving some consensus.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Maybe we require them to measure; this is Dixie Baker; maybe we suggest that the HIEs measure the accuracy. I like Paul's idea of their having a governance function as well.

Deven McGraw – Center for Democracy & Technology – Director
Well, we did include measurement in the previous set of recommendations on internal improvement HIEs are required to measure. They were included in that bucket of organizations.

(Overlapping voices)

Deven McGraw – Center for Democracy & Technology – Director
It's not layer one. It was in the internal improvement, number two.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Deven?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Yes.

Deven McGraw – Center for Democracy & Technology – Director
Yes, John?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Can we add to this C that you just typed in? Obviously it dovetails number two, but HIEs should be required to impose data quality requirements on participants and say something to the effect of, "And require participants that do not meet HIE established standards to undertake remedial improvement measures." Or something that goes ... if you're below the standard that the HIE adopts the HIE is required to work with you to try to improve.

Deven McGraw – Center for Democracy & Technology – Director
Right.

Paul Egerman – Software Entrepreneur
What does that mean though, required to impose? It sounds awfully—

Deven McGraw – Center for Democracy & Technology – Director
It sounds very legalistic doesn't it?

Paul Egerman – Software Entrepreneur
Yes. In other words, I'm wondering if that's really what we want to say. Maybe through the HIEs it should be required to establish affirmative patient matching programs to help their participants, instead of saying you've got to impose these data—it just sounds awfully—

M
But it's sort of like, at least where I live the health department has an A, B, C standard for restaurants. If you're an A you're okay. If you're a B or a C, you've got to undertake certain actions by a certain time to improve your cleanliness of your restaurant or they're going to shut you down.

Deven McGraw – Center for Democracy & Technology – Director
Right.

M
I think that patients have some expectations that someone, somewhere is looking out for their best interest and that everything is okay. I guess that's what I'm trying to get to. We could say it in a nice, kind, gentle way, but I think the HIE is in a position where it can enforce some type of minimum standard of performance with regards to patient matching or quality of data.

Paul Egerman – Software Entrepreneur
In order to participate in an HIE, right?

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Exactly. Exactly.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
But you don't want each one establishing a different level. I—

Paul Egerman – Software Entrepreneur

I think you do actually—

M
Yes, I think you do, because again, this is so related to the context.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
But it's also related to the region, because you hear stories about different regions where ... is more difficult.

M
Absolutely. I mean you have large, immigrant communities where 20% of the people have Social Security numbers—50% of the people have the same last name in small, ethnic communities. I mean there is so much stuff that you could do here. I think that what you're saying is the HIE has got to use some sort of judgment in these circumstances to determine whether people are good players in the exchange or not.

M
Exactly.

M
And I don't think you can establish some sort of absolute number at a national level that you expect people to achieve, because it's just not going to be relevant in every community.

M
By the way, the HIE is in the best position to do this because they have that relationship with the provider. I think, again, as I said before, really what the patient wants, the consumer wants is they expect and they want their information is being appropriately matched and that it's being safeguarded and the HIE can fulfill those roles and impose some level of ... for the participants.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
It strikes me that this expectation is a little bit like the HIPAA Security & Privacy rules, which don't specify exactly what you have to do, but specify a sort of broad requirement towards industry standard/best practice with a lot of flexibility for interpretation in specific settings.

Paul Egerman – Software Entrepreneur
This is helpful. I just have a question. What's written on the screen for letter B?

Deven McGraw – Center for Democracy & Technology – Director
Yes. That was from an old comment I think.

Paul Egerman – Software Entrepreneur
Yes. That doesn't quite fit I don't think. I think A and B, B is sort an elaboration of A I personally think, but I think this is a reasonable approach to this accountability issue based on where we are with measurement and then based on where the whole industry is.

Deven McGraw – Center for Democracy & Technology – Director
Yes, it seems that way to me too. Should we also include in the concept of what should be part of an HIE's affirmative program that they need to have some policies about what participants do with a wrong match?

M
Right. Well, you know, the idea of a DURSA, I guess you could put policy inside of a DURSA as well.

Deven McGraw – Center for Democracy & Technology – Director

Sure. Yes. The DURSA is just an enforcement vehicle, a DURSA, not the DURSA, right? I mean the DURSA is actually quite specific on what happens in a circumstance.

M
A DURSA-like agreement.

Deven McGraw – Center for Democracy & Technology – Director
Yes.

M
Yes.

Deven McGraw – Center for Democracy & Technology – Director
Yes. I mean the participation agreement is a mechanism of governance. So this needs a little bit of wordsmithing, which we can do off-line, but is the concept on?

M
Yes, I think so.

M
In B though it seems like we just decided that HIEs should establish their own standards but indeed, then we say ONC should convene stakeholders to develop measures of accountability—

Deven McGraw – Center for Democracy & Technology – Director
Wait. I just erased that. I'm sorry about that.

M
That's one way to deal with it.

M
Yes. Since we can't do it, let them do it.

W
But it's a longer-term strategy.

M
I know, but still, we're saying that the appropriate outcome is not a specific measure. I would say they need to establish some way of evaluating exchanges to make sure that they're doing what they need to do, which is using best practices to maximize the accuracy of matching.

Deven McGraw – Center for Democracy & Technology – Director
Hang on. Let me see if I got that other than the typo.

M
The third line—just the word measures—I would just say to develop best practices—

M
Yes.

M
—of accountability for matching accuracy rather than measures. If you just change that word measures to best practices that would be good in B.

M

I wouldn't even put in there of accountability, just best practices for matching accuracy.

M
Right. Exactly.

Paul Egerman – Software Entrepreneur
Okay. Although that is the segue to the next thing where we are going to be talking about best practices.

Deven McGraw – Center for Democracy & Technology – Director
Yes. So I think initially I thought of this as a longer-term strategy of looking to—once we get a little more evidence in the field about what the different HIEs are doing for different populations—to be able to set some benchmarks that we would hold people to versus— Paul is right. The next section is really just about development of best practices. All right.

So in terms of you all have gotten me persuaded that the HIEs are going to serve difference communities and there's not a one-size-fits-all approach to matching accuracy and that they should have some flexibility to figure it out. But if it's so without some level of standardization down the road that we couldn't look to creating some benchmarks that we would hold people to as we gather this evidence? That seems odd to me.

So now I'm back on Dixie's point that I certainly don't want to create incentives for people to not strive to hit industry standard with industry standard being shaped by population dynamics, use cases, etc.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Well, if I can substitute a medical analogy for a rug analogy, it would be like saying this medication is better for high blood pressure in most cases; therefore, we're going to mandate that everybody use it. That's' going to be our measure. What percentage of people get started on this medication? It's like you—

Deven McGraw – Center for Democracy & Technology – Director
I thought that's what—

David McCallie – Cerner Corporation – Vice President of Medical Informatics
If you're saying there's a local context then there's a local context. That's not going away in three years or five years or whatever. There's going to be a local context. Also, this document doesn't have to speak to what the end state of this is. I think we're looking for what's going to happen over the next few years, right? I guess I just worry when we call out things that are going to try to be very specific when we don't—

M
I agree.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
—that that's really the ultimate goal. The ultimate goal is not to end up with a number that says, "Your accuracy rate should be X."

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
At the same time, individual providers shouldn't have to be guessing about the standards that a particular HIE sets and enforces.

Paul Egerman – Software Entrepreneur
Yes, although I don't think individual providers will guess that. They'll just assume it's right.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

It's a community. The HIE is a community. It's not just a computer system, you know? It's a community of people, who are agreeing to work together—

Deven McGraw – Center for Democracy & Technology – Director
Right.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
In this trust framework—and they're going to need to have a conversation about these kinds of things—I don't think we're at a point where we can just say we're just going to report out on something in absolute numbers. We're just not there. I'm not sure you can even ever be there in relationship to something that's got this kind of local context.

Paul Egerman – Software Entrepreneur
So where are we on this discussion then? This part that's written as B, is that staying here or is that just a segue into the next topic of the best practices?

Deven McGraw – Center for Democracy & Technology – Director
No. I think—

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I like it. I like B.

Paul Egerman – Software Entrepreneur
Okay. Then we'll keep it there.

Deven McGraw – Center for Democracy & Technology – Director
You like B?

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I like it the way it is, the new B.

Deven McGraw – Center for Democracy & Technology – Director
Okay.

Paul Egerman – Software Entrepreneur
The new B.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
Yes, I like the new B.

Deven McGraw – Center for Democracy & Technology – Director
All right. Let's leave it as is.

Paul Egerman – Software Entrepreneur
Okay. Are we ready to move on to the next topic, which is best practices? So keeping—

W
….

Paul Egerman – Software Entrepreneur
—keeping the new B in mind, here is what we wrote: "HHS should establish a program to develop best practices, improving data quality and matching accuracy." We listed a number of bullets: Gather and disseminate evidence about what works. Establish programs for a transparency regarding the efficacy of matching algorithms. Pilot and test accuracy of matching strategies, where funds are available, fund

further development of innovative matching strategies, and finally, best practices for propagating record corrections. What do we think of all of this?

Deven McGraw – Center for Democracy & Technology – Director
Let me just say as an editorial comment, since we don't have any reporting in the earlier recommendations I'm going to delete that.

Paul Egerman – Software Entrepreneur
Okay.

M
I like this.

David McCallie – Cerner Corporation – Vice President of Medical Informatics
I like it too. I think this is a clear role that ONC or HHS—whoever we target it to—could perform.

Peter DeVault – Epic Systems – Project Manager
I agree with that.

Deven McGraw – Center for Democracy & Technology – Director
Well, that was part of the open question. Is this really just ONC's responsibility or does this have greater HHS implications where there are some other agencies, I think, with a strong interest in data quality, like AHRQ and CMS?

M
Well, it's—

Deven McGraw – Center for Democracy & Technology – Director
I mean we don't officially advise them, but—

Paul Egerman – Software Entrepreneur
It's interesting, because did that interesting little sidestep here where we expanded from matching accuracy to matching accuracy and data quality, which is a much broader topic, so data quality means is the problem list accurate. Is the medications list correct? There are tons of issues.

M
Maybe we should point that to data capture quality or the kinds of things we were talking about with the fields, making sure they have validation.

W
Right.

Paul Egerman – Software Entrepreneur
Well, it's just observation—

Deven McGraw – Center for Democracy & Technology – Director
It might have been unintended, Paul.

Paul Egerman – Software Entrepreneur
At least the way I read it is this was a bigger issue than patient matching; not that patient matching isn't by itself a big issue, but data quality is a big issue and an interesting issue.

M
Well, I think the scope of what we're doing here has to be kept to patient matching.

W
I think so too.

M
So let's just be explicit about that; that we're talking about data capture and accuracy with regard to the fields commonly used for patient management.

Paul Egerman – Software Entrepreneur
If that's the case then isn't the answer to this question that the target for our recommendation is ONC, because it's all about information exchange and patient matching as opposed to CMS or AHRQ?

Deven McGraw – Center for Democracy & Technology – Director
Yes.

M
I think that makes sense.

W
Yes.

Paul Egerman – Software Entrepreneur
Okay. So it seems like this was the easiest one, but it seems like we've got consensus on five. Are we ready to move on to number six, the next one?

Deven McGraw – Center for Democracy & Technology – Director
This is motherhood and apple pie.

Paul Egerman – Software Entrepreneur
This is great. We're on a roll.

Deven McGraw – Center for Democracy & Technology – Director
We're on a roll. I know. All right. This next set of recommendations gets to the role of the individual or patient improving matching accuracy. The draft recommendations says, "As individuals and patients can play an important role in identifying errors in their health and demographic information the tiger team supports the efforts of the Meaningful Use Workgroup and the Policy Committee to increase the access of individuals to their health information." This is acknowledging that there are ongoing efforts from other workgroups to improve patient access to data as part of meaningful use.

For those of you who were either present at the Policy Committee discussion on the call there was a lot of discussion about whether we would even go so far as requiring a patient portal for stage two or stage three. We're still gathering public comment on mechanisms for improving patient electronic access to their data, so we left this particular recommendation much more non-specific in light of those ongoing efforts. But we also had initially put on the table on our last call—we didn't get a lot of chance to talk about it—that some sort of electronic or automated means that individuals could use to notify entities of potential errors in their health information.

We've sort of framed this as a little exploratory. Dixie and the other members of the Standards Committee can tell us if it's too non-specific for them. But because it's very technical in nature, we have framed this as the Standards Committee should explore electronic/automated means that individuals can use to notify healthcare organizations of perceived errors in health information that could potentially and that that electronic automated means could then potentially be required in a later stage of certification. There is an example here, because this is really just an idea, but it's sort of piggybacking on an idea, I think, that the Certification and Adoption Workgroup had about a way to automatically report safety

issues. This would be reported by the providers; the safety issues would be reported by the providers, not the patient. In this case we're talking about whether or not there's a potential for an automated means of being able to alert, not necessarily correct, that record holder, that there might be an error in the data.

Then the final draft recommendation here is should HIEs be required to have policies and processes to support patient access to data and requests for corrections, keeping in mind that HIEs are business associates.

We didn't have any particular questions to tee up for you, but I'm sure you all will generate them.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Deven, I mean I'm okay with what's written. I guess the one area that I wonder whether we need to include is whether the patient should have the ability to see who accesses his or her information.

Deven McGraw – Center for Democracy & Technology – Director
That's a different topic, John. That's accounting of disclosures, which we haven't taken up.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Okay, because from a patient matching perspective, the reason why I bring it up in this context is that sometimes a patient will recognize that there is an error in his or her record because of the fact that it's been accessed by a provider they've never been to.

Deven McGraw – Center for Democracy & Technology – Director
But if the information itself is correct that's right, but I think that's a different kind of error.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Okay. I just thought I'd bring it up in this context. The individual has got to see the fact that that's occurred.

Deven McGraw – Center for Democracy & Technology – Director
Right. I think we're trying to deal with the simple issue of when an individual sees data in the electronic medical record held by their doctor or hospital and says, "That's not me."

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Right.

Deven McGraw – Center for Democracy & Technology – Director
Or, "That's not my right address any more," or etc.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
I understand that point, but I had the specific issue today where I got an alert on my PHR that says I'm supposed to go for a lab test and the lab test was issued by a provider I've never been to. Literally, that happened to me today. I wouldn't have known to even go to say something to something had I not seen the fact that I was being scheduled for a lab test, so I guess even knowing that a provider looked up my record may be an indication that there's something amiss.

Deven McGraw – Center for Democracy & Technology – Director
Right. That's a very good point, but it's an issue that I'd rather take up in the constellation of thorny issues about patient access to audit trails and/or the new accounting of disclosure requirements versus taking that on in this context.

Paul Egerman – Software Entrepreneur

I just want to say what you just said is fascinating; that you got an alert from somebody you never heard of before, who had looked at your PHR and asked you to get the laboratory test.

John Houston – Univ. Pittsburgh Medical Center – VP, Privacy & Info Security
Well, no. Actually, it turned out they misidentified me and they thought I was somebody else and they ordered a test for me.

Paul Egerman – Software Entrepreneur
Oh, I see.

Deven McGraw – Center for Democracy & Technology – Director
Wow.

Neil Calman – Institute for Family Health – President & Cofounder
I understand what you're saying, Deven, but I think, just like you called out our support for patients being able to access their information, I think we should call out in here that we support this as well, that we support the establishment of audit trails, which facilitate patients seeing where their information has been accessed through the exchanges. Even though that's being discussed somewhere else, we should support that. I mean that's an important piece. I guess, then, I have a question about it sounds to me like what you've written here is more about like looking at your record to see if there's something inaccurate in it. Not all of the information in the record has come through some sort of matching or exchange, so it sounds like this is sort of much broader than that.

W
Yes. Good point.

Deven McGraw – Center for Democracy & Technology – Director
Okay. So on your first point, Neil, I don't disagree with this, especially the way that you framed it because, number one, personally I would support it. But it also doesn't take on actually the issues that implicated. It doesn't really speak directly to whether patients should have access to audit trails ... very clearly to— I see—

Neil Calman – Institute for Family Health – President & Cofounder
Maybe, for example, I'm sitting here in my office and I've signed up to be able to be notified of some sort of notification any time anybody accesses my record. I'm sitting here in my office and all of the sudden I see that somebody has accessed my record from a hospital. Why would they do that? I'm not at the hospital. I mean it sounds to me like if there's any kind of transparency that people could understand it's that kind of transparency.

Deven McGraw – Center for Democracy & Technology – Director
Right.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I think number B here to me implies that this is a common occurrence, something like a blue button type of thing and I don't think that that's the message that we want to convey. I think it's more important from a standards perspective to have a feature in the EHR to correct errors that are caused in a patient record due to mismatching so that it's very clear to a provider which information was erroneously put there. This is the big issue; that once erroneous information gets in the record how you deal with it. I think that that's more of a standards issue and providing consumers a way to inform their providers that there's incorrect information I think is more of a policy issue. So I would suggest B be changed to the Standards Committee to explore standards for enabling erroneous information placed in EHRs to be removed or invalidated.

Paul Egerman – Software Entrepreneur

That's the whole corrections issue.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Exactly.

Paul Egerman – Software Entrepreneur
But why Standards Committee?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
It's an EHR issue in my mind.

Paul Egerman – Software Entrepreneur
But why is the Standards Committee the one that explores that? That's actually the next topic is corrections, but why Standards Committee? Aren't there policy issues there? I mean the policy issues related to information exchange and there's also HIPAA already has some statements about corrections.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I agree with that, but B here is about electronic Standards Committee should explore electronic, automated means. I don't think that's appropriate for the Standards Committee. I think we should be focusing on EHR technology and I don't see this as an EHR technology thing.

Deven McGraw – Center for Democracy & Technology – Director
I think we saw it as potentially part— Let me ask you a quick question. Are these recommendations still on your computer screen, folks?

Paul Egerman – Software Entrepreneur
Yes they are.

Deven McGraw – Center for Democracy & Technology – Director
Okay. So, Dixie, this is now C. Maybe you don't have access to it.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Yes, I have it here. I was just reading on my paper instead of looking up. Yes.

Deven McGraw – Center for Democracy & Technology – Director
All right. We were talking about as part of a portal.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Yes. I would say and I would agree with Paul again, that's a policy issue. I think as a policy patients should have some means of reporting errors that they find in their record, but I don't think it's a Standards Committee EHR thing. The Standards Committee can with HIE things as well though, right? I mean they're not limited to EHRs.

Deven McGraw – Center for Democracy & Technology – Director
Right.

M
... it says, "The Standards Committee should explore standards for removal of erroneous information. It's really not the standards for removal. It really should explore technology standards that make it easier to report, easier for patients to report erroneous information.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I don't think a patient, if I found that somebody else's information is in my record I don't think I want to go to a portal and hit a button. I think that's something that you really want to discuss with your provider.

Paul Egerman – Software Entrepreneur
Well, that's true, but maybe there's something else that's very simple, like it has your street address spelled wrong or it has your middle name spelled wrong. Then maybe what you want to do is you just want to make it easy to report that.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Yes, but I think we're talking about patient matching. We're not talking about those minor—

W
They're part of patient matching. It's part of accurately capturing the data.

M
Yes.

M
Yes. If they spell my middle name wrong—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
... talking about instead of when I read this what I thought you were talking about Is if I see that somebody else's information is in my record I should have a button to push and I just don't think that that's what should happen if I see somebody that a matching error has been made. I agree with you that it would be good to provide consumers an easy way to correct information that's relevant to matching.

Paul Egerman – Software Entrepreneur
It's not correct. It's to report—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Right.

Deven McGraw – Center for Democracy & Technology – Director
Yes.

Paul Egerman – Software Entrepreneur
—information that they believe is inaccurate. The example I would give is I looked and I thought that they had spelled my middle wrong I think you want to make is easy for me. I don't necessarily want to call my physician and tell him that. I think what I want to do is be able to talk to something and say it's Lawrence, L-A-W, and not Laurence, L-A-U.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Yes. I think if that's what we mean we should just make it clear that that's what we mean. I understand what you're saying, Paul, that this was intended to provide consumers a simple way to correct information about them.

Paul Egerman – Software Entrepreneur
Yes.

M
So the analogy is the credit reporting bureau audit requirement that they have to live up to. They have to give you a copy. If you see a mistake, you can report it to them and they can initiate a process to correct it.

Paul Egerman – Software Entrepreneur
I had a question about what is now letter D, which is do most HIEs have patient access?

W
Yes.

Paul Egerman – Software Entrepreneur
This needs to be qualified for HIEs that provide patient access. If you have a federated model maybe there's no reason to have patient access—

W
I think—

M
Except maybe to determine accuracy of matching.

Paul Egerman – Software Entrepreneur
Yes, except if I'm a patient how will I know to look over there?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I think C covers it. I don't think we need D.

Deven McGraw – Center for Democracy & Technology – Director
Well, B, actually, the audit trail point that Neil made. I mean that covers the John Houston circumstance. I think Paul has a good point; that we've got HIEs and a number of models out there. If they don't hold any data, for example, then they don't have anything for patients necessarily to access, but if they do centralize and hold data, one could make an argument that they ought to be sort of held to the same standards of access.

Paul Egerman – Software Entrepreneur
But even if they don't hold data, if they're doing matching they hold something.

M
Well, the hold the record of the matches that are made, just like you said before, so that you can determine if there's a match that doesn't look right you, where your data went somewhere.

Leslie Francis – NCVHS – Co-Chair
There is another patient privacy concern here, which is that if patients ever exercise a request that a particular provider's information not go into the exchange they might want to be able to see not just what's in their—

Paul Egerman – Software Entrepreneur
Interesting.

Leslie Francis – NCVHS – Co-Chair
—health records, but also what's in the exchange.

Paul Egerman – Software Entrepreneur
Yes. That's a great point. They're really interested in the absence of information. They wanted to validate that there's nothing there—

Leslie Francis – NCVHS – Co-Chair
Right.

Paul Egerman – Software Entrepreneur
—or a particular provider perhaps is not.

Deven McGraw – Center for Democracy & Technology – Director
Right, but that sounds like something to add to our wrap-up of transparency recommendations versus something— What's the relationship of that to matching?

Leslie Francis – NCVHS – Co-Chair
It's not necessarily related to matching. It's just something not to forget about and I thought it was worth raising at this point—

Deven McGraw – Center for Democracy & Technology – Director
It is.

Leslie Francis – NCVHS – Co-Chair
You were talking about audit and so on.

Deven McGraw – Center for Democracy & Technology – Director
That's a really good point, Leslie. So what are we doing with D? Are we still on?

Paul Egerman – Software Entrepreneur
Yes. The part that I'm having trouble with D is to what extent HIEs are required in the first place to give patients access to the data.

Deven McGraw – Center for Democracy & Technology – Director
They would if their business associate agreement requires it.

Paul Egerman – Software Entrepreneur
So it should say to the extent HIEs are required to provide access to data, then they should be also required to have policies, right? If required to provide access I think the first thing should be HIE.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I don't think that that's needed, because C doesn't say who, so C could apply to the individual providers or HIE.

Deven McGraw – Center for Democracy & Technology – Director
Yes, but that's just a reporting technology and it's about technology, Dixie, versus policy, having a set of policies and procedures in place.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Why are we limiting D to HIEs? Shouldn't it be providers as well, the part starting after the comma?

Deven McGraw – Center for Democracy & Technology – Director
Except at least for covered entity providers, they have some pretty clear instructions about what they have to do under HIPAA. In the business associate context, it's basically left a little nebulous.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
And HIPAA doesn't address requests. I would make D applicable to both, HIEs and providers, because I don't think HIPAA requires that they make it visible, requests for corrections.

Paul Egerman – Software Entrepreneur
Okay, well let's do a little bit of wordsmithing, but we can look at that.

Deven McGraw – Center for Democracy & Technology – Director
Yes. Yes.

Paul Egerman – Software Entrepreneur
So I think we're done with this one and ready to move on to number seven.

Deven McGraw – Center for Democracy & Technology – Director
Yes, except we have ten minutes.

Paul Egerman – Software Entrepreneur
That's okay. I think I can do it fast.

Deven McGraw – Center for Democracy & Technology – Director
Okay.

Paul Egerman – Software Entrepreneur
Number seven is about propagating corrections. Then it says in yellow, "This is really all new. We may need to devote a separate meeting to discuss," and considering the fact that we've only got ten minutes left I'd like to suggest that propagating corrections is actually a different topic, because it relates not just to patient matching, but there's also propagating corrections about other data. I mean suppose the system says the patient is allergic to penicillin, but the provider determines that's inaccurate; it's not penicillin. It's another drug. How is that propagated to other participants in the exchange? So it's an interesting topic. I think it's broader than patient matching, so I think we defer on this topic to another day.

Peter DeVault – Epic Systems – Project Manager
I'll second that.

Paul Egerman – Software Entrepreneur
Pardon me?

Peter DeVault – Epic Systems – Project Manager
I'll second that.

Deven McGraw – Center for Democracy & Technology – Director
All in favor?

Participants
Yes. Good.

Deven McGraw – Center for Democracy & Technology – Director
All right. That's fair. Paul, I like the way you dealt with that so quickly.

Paul Egerman – Software Entrepreneur
So basically, what's happened is we actually have completed our patient matching/patient linking recommendations. Deven and I need to write it up and we'll keep in mind David McCallie's original suggestion that we have some either conclusion or introduction or something that makes the statement about it's due to multiple factors. It's not technology, but when attention is paid and when it's handled as a continuous learning and improvement process there are multiple effective techniques to do patient matching, but I believe we've concluded. So I think the next steps will be that Deven and I need to write it up and we'll probably pass it by you one more time—

Deven McGraw – Center for Democracy & Technology – Director
We definitely will pass it by you one more time, but we have time to do that.

Paul Egerman – Software Entrepreneur

Because we have the Policy Committee meeting on February 2nd, but what I hope to do is put it in front of the Policy Committee and see if we can get agreement on that and then we can move on to whatever our next exciting topic will be.

Deven McGraw – Center for Democracy & Technology – Director
Yes, which along those lines, we are working up a schedule for you all to discuss, have input on over the next several months in terms of continuing to populate a privacy and security framework. We will also have some time to discuss the PCAST Report and how well that harmonizes with recommendations we've already put on the table.

Paul Egerman – Software Entrepreneur
That sounds good. Does anybody else have any comments before we open ourselves for public comment?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I just have one comment and that is, Paul, we have a tiger team meeting on the day before our PCAST meeting. I know that some people are on this tiger team, myself, but not only myself, that would be traveling that day.

Deven McGraw – Center for Democracy & Technology – Director
Oh.

Paul Egerman – Software Entrepreneur
I'm sorry. What day are you referring to, the 24th?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
February 14th.

Paul Egerman – Software Entrepreneur
Okay. Our next tiger team meeting is—

Deven McGraw – Center for Democracy & Technology – Director
February 4th.

Paul Egerman – Software Entrepreneur
—February 4th. Right.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Right. It's the one after that, the 14th.

Deven McGraw – Center for Democracy & Technology – Director
Yes. It's the one before your big PCAST Workgroup day.

Paul Egerman – Software Entrepreneur
Oh, I see what you're suggesting. Okay. I have no idea what we're going to do with that, but that's a good point, Dixie. We'll look at that, because I understand. You'll be in transit from the West Coast.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Right.

Deven McGraw – Center for Democracy & Technology – Director
Others may be as well.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes, others will be as well.

Paul Egerman – Software Entrepreneur
That's a little bit of a challenge. Thank you for pointing that out. I'm not sure how—it's a little bit hard to change, but we'll see what we can do. Any other comments?

Deven McGraw – Center for Democracy & Technology – Director
Thank you, everyone, for a terrific call. I think we need to move to the public.

Paul Egerman – Software Entrepreneur
Absolutely.

Judy Sparrow – Office of the National Coordinator – Executive Director
Okay. You're faster than a speeding bullet. Operator, can you check and see if anyone from the public would like to make a comment?

Operator
Yes. You have comments.

Judy Sparrow – Office of the National Coordinator – Executive Director
Thank you. Could you please identify yourself?

Lorraine Fernanz – IBM
This is Lorraine Fernanz from IBM. I commend you guys for all of the work you've done in the last hour and 45 minutes. Very impressive. Two comments.

Number one, when you first discussed data standards, the format and the content, I think there will be some tough work ahead in that area because there are states; I can think of California and New York for example, that do have state data reporting agencies already and they have required content, format and some normalization procedures they use. So you might want to consider, maybe do a little survey of what states are already requiring certain fields and formats that ....

Then the second one was I think you're spot on in talking about data quality standards and the fact that they're a part of governance and building trust. That is certainly what I hear from all of the regional data exchange organizations I work with, as well as the states. So I think you're right on track with where the industry needs to put that. Okay.

Judy Sparrow – Office of the National Coordinator – Executive Director
Thank you, Lorraine.

Deven McGraw – Center for Democracy & Technology – Director
Thank you, Lorraine.

Judy Sparrow – Office of the National Coordinator – Executive Director
Any other comments? Okay. Deven. Paul.

Deven McGraw – Center for Democracy & Technology – Director
Thank you, everyone, for participating today. Keep an eye on your e-mail for the further wordsmithing of our conversation, but we really appreciate all of your efforts and the time you take to be on these calls.

Paul Egerman – Software Entrepreneur
Yes, it was a great call. I was trying to think of David's metaphor. It was very interesting, but the whole project is like a magical, mystery carpet ride or something. This was great.

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We thank you for your leadership.

Deven McGraw – Center for Democracy & Technology – Director
Thank you for not singing it.

Paul Egerman – Software Entrepreneur
Or especially not trying.

Participants
Thank you. Good-bye.

Deven McGraw – Center for Democracy & Technology – Director
Good-bye, everyone.

Public Comment Received During the Meeting

1. Does the requirement for demographic data rule out any populating of the data to the EHR by an inbound HL7 ATD interface from a registration system? Must all demographic data be directly entered into the EHR?

2. Comment on issues raised about names and addresses. It was pointed out that a change of name when a woman gets married could be an issue in matching. Coming from Puerto Rico we have much larger concerns about name. And this will apply to many "Latin" individuals living throughout the States. Names are based on Spanish conversion which uses 2 last names. Typically systems here have separate fields for those names. How a person has reported their name to different providers can be significant. Depending on situation a woman may use her husband's name when married but is more likely to retain her own. Even if a woman uses her husband's name (common if they lived stateside) hospitals here will always record her using her unmarried name.   Addresses are frequently an issue as well as most require at least two lines. And typically the order of street name and house number is regularly the reverse of stateside convention. And it may be written out in Spanish in one place and English in another. I

3. With the idea of the "testing" a participant's accuracy, and possibly removing them from the HIE if they do not improve, assumes that the HIE has no part in the process of patient matching accuracy and therefore do not contribute to the performance. The processes an HIE uses for patient matching cannot be assumed to be neutral in terms of the performance of each participant unless every participant has the same software, same patient population, same data entry etc.

4. Also, Dixie's question about EHR redesign may be every bit as much redesign of registration screens by hospitals and EPs and less software development requirement.

5. Corrections - if the HIE is not the source of the data, there is not much point in the HIE correcting errors, so will the point be that the HIE must direct the correction request to the source. The source to the HIE may not be the direct source of the data in error. This could get quite complicated and confusing for the patient.